

Arrhythmogenic (Right Ventricular) Cardio Myopathy (ACM)



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Our Heartfelt Goal: Moving Forward **Together** 



www.arvc-selbsthilfe.org

#### What is ARVC?

ARVC, or more generally ACM, is a primarily hereditary heart disease in which heart muscle cells are replaced with fat and/or connective tissue.

This replacement process can lead to cardiac arrythmias, and more rarely, to heart failure or even sudden cardiac. death.

#### **POSSIBLE SYMPTOMS**

- Palpitations, skipping or racing heartbeat
- Dizziness or fainting
- Pressure or pain in the chest
- Shortness of breath, breathlessness.
- Fatigue or exhaustion

#### **DIAGNOSIS**

The presence of disease may be indicated by ECG, echocardiogram, or MRI results, or if there is a family history of sudden cardiac arrest or death. Genetic testing may help to confirm the diagnosis and identify at-risk relatives. Not every carrier of a genetic mutation will develop clinical symptoms within his or her lifetime.

#### **TREATMENT**

The symptoms of ARVC can be treated with medication and/or with a catheter ablation procedure. To reduce the risk of sudden cardiac death, an implanted defibrillator is recommended for patients with high-risk profiles.

## ACM, AVC, AC

SHORT:

IN

Umbrella term for all types, including biventricular

#### ARVC, ARVD

Typical right-dominant presentation

#### **ALVC**

Left-dominant variant



#### A=Arrhythmogenic

Arrhythmiacausing

#### V = Ventricular

Ventricleaffecting

#### C(M) =Cardiomyopathy

Disease of the heart muscle

#### D = Dysplasia Malformation

(outdated term)

R = riaht

L = left



"Receiving the diagnosis of ARVC can have an enormous impact on one's life. We're committed to ensure that those affected receive comprehensive care, and we provide resources that support them throughout their challenging journey."

Ruth Biller, Chairperson ARVC-Selbsthilfe e.V.

#### We're here for you!



#### **LOCAL CONTACT PARTNERS**

Across Germany, members of our group are available for conversation and communication. In some regions, there are also in-person meet-ups.

For the most up-to-date contact information, please visit our website.

#### **ARVC-HOTLINE** & E-MAIL

For questions about the disease, or the organisation

+49 163 - 18 47 521

info@arvc-selbsthilfe.org

#### **ARVC-TELEPHONE HELP LINE**

For a chat, if you only want to talk

+49176-57799498

or austausch@

arvc-selbsthilfe.org

#### **HOMEPAGE**



On our website, you can find the most up-todate event schedule, more information about ARVC, and opportunities to get on our mailing list or become a member of our association.

### www.arvc-selbsthilfe.org

#### ARVC-Selbsthilfe e.V.

c/o Ruth Biller • Fastlingerring 113 • D-85716 Unterschleißheim





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Bundesverband Herzkranke



Patient Advocacy



European Reference Network for rare or low prevalence complex Heart Diseases

**EURORDIS** 









### INFORMATION CLEAR & UP TO DATE

Have you just recently received the diagnosis and do you have a lot of questions? Or have you been living with this disease for a while, but still want to understand some things more precisely?

We'll help you find the answers you're looking for.

#### • LECTURES - LIVE & ONLINE

Concentrated knowledge on chosen themes regarding ARVC/ACM

#### Q&A-SESSIONS

Patients ask - experts answer

#### • HOMEPAGE

Extensive information on living with the disease www.arvc-selbsthilfe.org

#### YOUTUBE CHANNEL

Our videos are here: <u>ARVC-Selbsthilfe e.V.</u>



How will

the disease

progress?

Jutta Wevers,

ARVC patient

"The conversations

really helped me to come to terms with

this diagnosis, which

so suddenly affected

almost all my family

understand what the

There is a sympathetic

ear for all questions."

ARVC-SELBSTHILFE

members and to

risks were for us.

What exercise

am I still allowed

to do?

ARVC SYMPOSIUM

FAMILY,

PROFESSION.

HOBBIES?

WHAT DO I HAVE TO

**WATCH OUT FOR?** 

ARVC-Selbsthilfe Meet-up with experts

### MEET-UPS REGIONAL & CROSS-REGIONAL



Do you wish to have contact with others affected by ARVC? Do you want to share some of your own experiences and learn how others are coping?

Together, we can find our way out of crisis and develop new strategies for managing this disease

#### • WEEKEND MEET-UPS

A weekend in Germany with the whole "ARVC Family". A great opportunity to meet new people, catch up, get useful tips and gain insight into the life of others.

#### • REGIONAL MEET-UPS

Meet-ups with others affected by ARVC from your area, organised by our local partners in Germany.

#### ONLINE MEET-UPS

Meet other ARVC patients without travelling, from the comfort of your own home.

#### PATIENT FORUM

Ask questions, discuss personal topics, and share stories. A moderated online community is available on the RareConnect platform.

ALSO FIND US ON:







#### **FUTURE PERSPECTIVES**

**SCIENCE & RESEARCH** 

ARVC is a rare disease, for which there is still a great need for research. We support research on basic knowledge of the disease mechanisms, the faster achievement of a diagnosis and the development of future treatment strategies.

Vero Lüscher, ARVC patient and Board Member

"The day-to-day living with ARVC was very hard for me in the beginning. Am I allowed to exercise; what is it like to live with a defibrillator; what else do I have to worry about...? Connecting with others affected by ARVC is very helpful with all of that."



Moving Forward Together



# • STUDIES, PATIENT REGISTRIES AND BIOBANKS

hospitals and research

Financial and organisational support for various projects

#### • TRAINING & EDUCATION

Participation in (inter-)national conferences, literature review of state-of-the-art medicine and recent study results







Prof. Dr. med. Eric Schulze-Bahr, Speaker of the Scientific Advisory Board

"The ARVC-Selbsthilfe provides outstanding help with everything that is important: a personal, psychological and medical understanding of and information about your disease."



